



Transplant Times

Newsletter of the Transplant Awareness Organization of Greater Rochester

Providing support, understanding, education and resources for transplant recipients candidates and their families.

February / March 2011

www.tao-rochester.org

1.888.664.1463

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TAO Membership dues are now due for the upcoming year.

Your membership dues are used for funding support initiatives and social activities of TAO.

TAO Meets

NEW DAY & LOCATION

**3rd Monday of the Month
Christ Episcopal Church
Fellowship Room
36 South Main Street
Pittsford, NY
(See directions and details
on page 2)**

Let me begin by wishing all of you a Happy and most of all a Healthy New Year. It may be a little early to look forward to spring. However, we at least have the benefit of gradually longer daylight hours, which helps to lift one's spirits!

In early December the board and several other TAO members participated in a Strategic Planning workshop to look at the progress that the organization has made since the last workshop three years ago, and to refocus our efforts to serve the transplant community better. We are now in the process of prioritizing our action plans. One of the changes that we have made immediately, in response to feedback we have received from you, is to move our meeting site from the Al Sigl Center to a friendlier, quieter environment. Beginning with the first membership meeting of 2011, we will be meeting at Christ Episcopal Church in Pittsford in their Fellowship Room. A map showing the location of the church in Pittsford village, together with information on parking, is included in this issue of the Transplant Times. In addition, we will make sure that signs are in place inside the building to get you to the Fellowship Room on the evenings of each meeting. I note that for those who need it, handicap access is available. The other immediate change is a change to our meeting schedule. We are switching from the third Wednesday of the month to the third Monday. The next membership meeting is therefore Monday, February 21st. Again, based on your feedback, we believe this change should work fine for most members. Another related initiative we would like to implement in the future is some kind

A Message from the President



of ride share program to get members to our monthly meetings. We are aware that there is a need for such a program given that some TAO members are not able to drive at night and therefore unable to get to our meetings, particularly during the winter. More information on that will be communicated when our plans are better defined.

In the meantime, we are working to bring you some interesting speakers in the coming months. We look forward to seeing as many of you as possible at those meetings.

Geoff Foley

Membership Meeting Guest Speakers / Topics

February 21, 2011

Christine M. Hay, MD - *Transplant Related Infections and Prevention*

March 21, 2011

Michael Robinson - *Estate Planning*

New TAO Meeting Location

Starting with the February 21 meeting, TAO has relocated to Christ Church at 36 S. Main Street in Pittsford.

Directions to Christ Church Pittsford (36 S. Main St.)

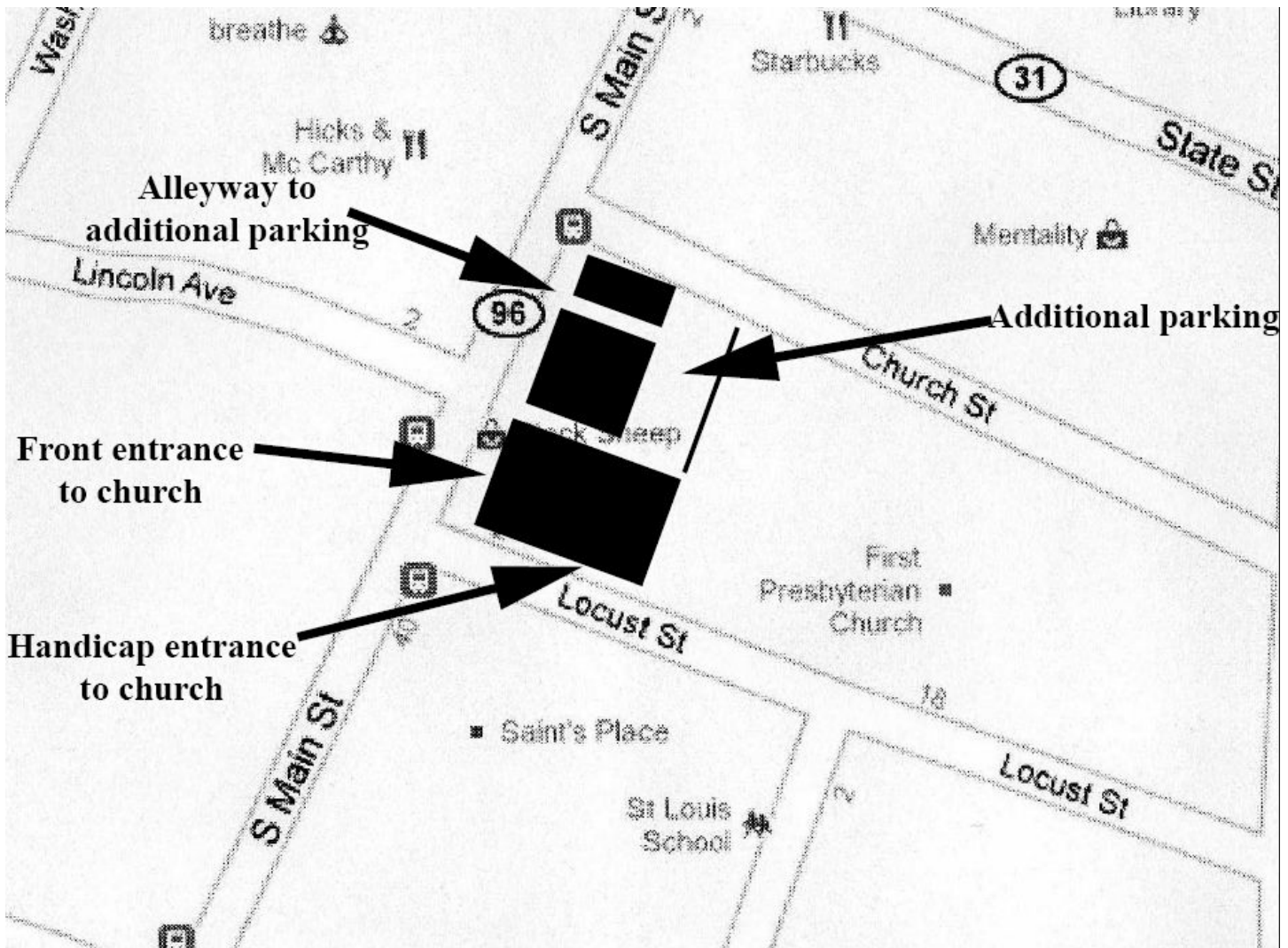
The church sits at the corner of Locust Street and South Main Street in the village of Pittsford (see map). The main entrance is on Main Street. The handicap entrance is on Locust Street.

Parking

Street parking can be found all along Locust Street and on Main Street. There are two handicap parking spaces in front of the church on Main Street. There is additional parking behind the storefronts on Main Street (as shown on the map). This will accommodate about six to eight cars.

Getting to the Fellowship Room

If entering the church from the main entrance, turn left after entering and take the short staircase "up" on your right. The Fellowship Room is at the top of the stairs on the left. If entering from the handicap entrance on Locust Street, either take the staircase "up" on your left or take the elevator on your left "up". At the landing enter the church sanctuary and cross in front of the altar to the door on the other side. Walk up the ramp and at the top of the ramp, turn left and go down the hall to the Fellowship Room on your right.



Hope Lodge Shelters Visiting Patients

Reprint from Rochester Democrat and Chronicle - Rochester, N.Y. Ernst Lamo Author

Wanting to create a comfortable environment for those going through one of the toughest battles of their lives, American Cancer Society officials Thursday showed off the renovated, 30-bedroom B. Thomas Golisano Hope Lodge Hospitality House.

The lodge, where out-of-town cancer, transplant and trauma patients and their caregivers can stay when they travel to Rochester for treatment, is located at 1120 S. Goodman St. on the Colgate Rochester Crozer Divinity School campus. It is in the former two-wing Trevor-Eaton student dorm, which was transformed in a \$10 million restoration project.

The B. Thomas Golisano Hope Lodge Hospitality House is one of 30 Hope Lodges nationwide. The American Cancer Society covers lodging for cancer patients, who must be referred to the hospitality house by a social worker. The facility provides low-cost lodging for transplant and trauma patients and their caregivers.

The facility features a kitchen, dining room, library, fitness room and a bedroom, where patients are given a journal to record thoughts and leave it for the next resident to provide a level of support and encouragement.

"We hope people come together and share their experiences, which helps everyone get through this difficult time," said Lorraine Clements, Hope Lodge Hospitality House director. "It's a scary time in a person's life with many challenges, so we are offering not only a nice place to stay but hope and peace of mind." With medical bills, hotel rooms and the emotional stress of a life-changing disease, patients say the facility offers a home away from home.

Board of Directors & Officers

- | | |
|--------------------------|------------------------|
| President | <i>Linda Barnard</i> |
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| Treasurer | <i>Rob Kochik</i> |
| <i>Dave Johnson</i> | <i>Janice Odenbach</i> |
| Secretary | <i>Jerry Runion</i> |
| <i>Bev Shank</i> | |

United Network for Organ Sharing

Candidates listed as of 1/16/2011

- 87,683** Kidney
- 16,113** Liver
- 3,165** Heart
- 2,213** Kidney/Pancreas
- 1,791** Lung
- 1,414** Pancreas
- 264** Intestine
- 68** Heart/Lung

110,214 TOTAL

Total may be less than sums due to patients in multiple categories

www.unos.org

Join a Committee
 Sunshine , Newsletter,
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Transplant Anniversaries

JERRY BLUFF	LUNG	FEBRUARY 2004
MATTHEW FELO	LUNG	FEBRUARY 2007
PATRICIA LEGGE	KIDNEY	FEBRUARY 1996
SHIRLEY NEWMAN	KIDNEY	FEBRUARY 2008
JOSEPH NOLAN	KIDNEY	FEBRUARY 2006
AISHA O'MALLY	HEART	FEBRUARY 2004
GREG POST	KIDNEY	FEBRUARY 2008
SCOTT SANFORD	LIVER	FEBRUARY 2009
CYNTHIA BOYER-GREEN	KIDNEY	MARCH 1996
RITA CALLAGHAN	LIVER	MARCH 2001
JANA CURRIE	DOUBLE LUNG	MARCH 2008
KAREN GLEDHILL	KIDNEY	MARCH 1982
ROBERT HADSELL	LIVER	MARCH 1997
THOMAS LOUER	LIVER	MARCH 2004
PAULA MCKAY	KIDNEY	MARCH 1995
JAN SHARP	KIDNEY	MARCH 2005
DENNIS WITTMAN	LIVER	MARCH 2007

An Informative Look About Vitamin Water Beverages



As we walk through the abundance of beverage selections, vitamin waters have found their place in this competitive commodity.

Looking at the pro's and con's of this particular idea for a beverage we first look to the basics = water. Water, a vital importance to the diet for without it we would cease to exist in days versus weeks without food.

60-70% of the human body is water. To feel optimum it is good practice to replace water in our bodies just like the oil in an engine. Water assists the body to carry nutrients to cells while flushing waste and toxins out (in transplant this is very important), lubrication and tissue composition, and temperature regulation. The recommended amount to drink is 6-8 glasses per day unless your medical physician has deemed otherwise or if losses are more in the event of a: fever, excessive sweating, vomiting or diarrhea.

So why mess with a good thing? Just like any food or beverage we first need to decide the purpose to purchase vitamin water, financial gain/loss, and most importantly the quantity drank before deciding the disadvantages.

The question: WHY? In the number of years I have been discussing food with people my guess is... the most frequent answer heard, would be because.... I like it. This final answer is a result of our many senses working together – sight, sound, taste, touch and smell to reach the logical conclusion based on our own individual opinion to reach into our wallet and purchase it. Marketing professionals love this revelation. As individuals we do to!

*Elizabeth Keirstead RD, CNSD
Transplant Nutrition Specialist
University of Rochester Medical Center*

There are 11 or more different companies offering products with a variety of flavors, colors, vitamins/additives and calorie level combinations. As a transplant nutritionist, I advise tread with caution.

- Check, as with any food/drink, by first looking at the portion size. If you are concerned about sugar calories pay close attention. Most bottles list 2.5 servings, so do the math.
- Water is very thirst quenching but this effect can be reduced when there is added sugar. For weight control or blood sugar concerns this is not a choice of beverage you want to over consume. For example, in comparison to soda; some waters contain 100-125 calories; soda 140 calories.
- False promises – a grey area. The U.S. population is not a group at risk for vitamin deficiencies especially for those who eat a VARIETY of FOODS and FOOD GROUPS. Water soluble vitamins added to these products will be eliminated in urine if your diet is sufficient in these vitamins.

My worry, on this last point, is the use of a product in moderation. Harm can come when consuming products containing herbals, caffeine and vitamins in excess – remember the portion size.

So the next time you consider the benefits to vitamin water I hope you have your decision made. If it is because you like it and it is within your diet guidelines as moderate then enjoy! For now, Vitamin water has found its place in the beverage isle just like all the others.

NY State Donate Life Registry: Electronic Signature Law Passes

This past July, The Electronic Signature Act was passed into law by Governor David Patterson.

Once the law is implemented it will eliminate the need to download a hardcopy of the enrollment form from the NY State Department of Health, complete it, sign it and then mail it back to the NY State Donate Life Registry.

Surplus Medications

Do you have medications that you're not using and don't know what to do with them?

St. Joseph's Neighborhood Center 417 South Ave Rochester (585) 325-5260 will take any medications current or expired. Please drop them off at their location for disposal.

The family of Jacob Rian Campbell came to Strong Memorial Hospital for the preparation of Jacob's floragraph for the 2011 Donate Life Rose Parade Float.

From L to R
Andy, Ben and Holly Campbell



The Green Lantern Inn in Fairport was the setting for TAO's Holiday Recognition Dinner on Saturday, January 8, 2011. TAO President Geoff Foley greeted about 40 members and recognized some members that have passed since our last gathering; former Vice President Sandy McNitt, Board member Jim Fyfe and member Frank Imburgia who was active in the volunteer programs at the hospital. Mike and Sally Stelljes were recognized for their volunteer efforts at the hospital and their time on the TAO board. Jerry Runion was lauded for accomplishments made during his tenure as President of TAO. Geoff also thanked Elizabeth Keirstead, RD for her contributions to the Transplant Times.



Dave McNitt & Tony Gledhill



Jerry Runion
Jana Curie
(background)



Terry Sullivan & Kathleen McCaffery



Bill & Carol Pftutner, Lois Foley

Janice Odenbach brought a bag of her handmade scarves and sales were brisk! Our very own president is pictured modeling one of Janice's creations! All had a good time and no one went home hungry! We look forward to seeing everyone soon at upcoming meetings and at our summer picnic.

Contributions

We wish to acknowledge and thank the following individuals and / or organizations who made contributions to TAO.

*If we omitted you, please let us know so that we may post in next issue. **THANK YOU.***

Geoff Foley
Ralph M. Toscano, Jr.
Dennis & Eileen Kovel

In memory of Sandy McNitt:

Janice Odenbach

In memory of Jim Fyfe:

Todd A. Heller
Christine & Tom Arcara

In memory of Frank Imburgia:

Chris & Tom Arcara

In memory of Linda Marie Serenka:

*Stephen P. Nagel
Jennifer D. Anderson
Clancy Real Estate, LLC
William J. Mather, Sr.
Diane Davidson
Thomas O. Pandick
Ultra Electronics
Bonnie Edelstein
Bette F. Serenka & Lawrence Cole*

In memory of Ross M. Scott:

Janice Odenbach

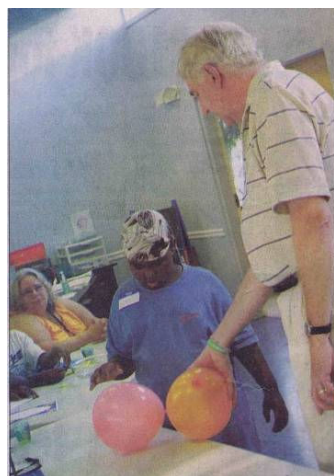
In Kind:

Kathleen McCaffery
Debbie Yendrzeski



Dr. Yousuf Khalifa gave a presentation on Corneal Transplants at the November TAO Meeting

Did You Know. . .



Meet the Science Guy

Geoff Foley, a retired Xerox physicist and holder of 75 patents, demonstrated static electricity with fourth-grader Asha Bakari as part of the "Professionals Speak" summer program at Learning Links of Fairport United Methodist Church.

Gift IDEAS

A contribution to TAO in honor of or in memory of a loved one, special person or relative is always a thoughtful gift. It is a gift of caring that you can give on any occasion - a birthday, an anniversary or a special holiday.

Please make your check payable to:
Transplant Awareness Organization
Mail to: TAO, PO Box 23552
Rochester, NY, 14692-3552

Wishes of Wellness To...

Dan Newhouse, Laurie Packard and Meg Dougherty



US-based Indian Creates First Artificial kidney

TNN, Dec 4, 2010, 12.58am IST

NEW DELHI: US-based Indian origin researcher **Shuvo Roy** has created the world's first implantable artificial kidney. What's sensational about Roy's creation is that the organ, no larger than a coffee cup, will be able to mimic the kidney's most vital functions like filtering toxins out of the bloodstream, regulate blood pressure and produce the all-important vitamin D.

The artificial kidney has been tested successfully on a small number of animals. Large-scale trials on animals and humans are expected over the next five years. Once available, and if affordable, this creation by the Roy-led team at University of California will do away with the need for kidney dialysis.

This will be a boon for all patients with chronic kidney disease (CKD). At present in India, of the 1.5 lakh new patients who suffer from end-stage renal failure annually, only 3,500 get kidney transplants and 6,000-10,000 undergo dialysis. The rest perish due to an acute shortage of dialysis centers and nephrologists to man them.

CKD is rising at a rapid pace in India and the majority of those who perish are either unable to find a suitable organ for transplantation or are unable to pay for the high dialysis costs.

According to Roy, the device has a filtration section to remove toxins from the blood, alongside a compartment with renal cells to conduct other functions of a kidney. He believes the artificial kidney could last for decades and require no pumps or batteries. Patients wouldn't require anti-rejection drugs (as is required after transplants) either because there would be no exposed natural tissues for the immune system to attack.

The University of California team is awaiting approval to conduct larger scale animal and human trials. Already, it has successfully tested the implant in a few rats and pigs.

"The payoff to the patient community is tremendous," said Roy. "It could have a transformative impact on their lives... With the right financial support, I think we could reach clinical trials in five years. But it's hard to say how long after that it becomes commercially available due to the uncertainties of the FDA and commercialization prospects."

Don't Forget . . .



**Flu Season is here.
Get vaccinated!**

Save The Date . . .

TAO Organ Specific Support Groups

Are you interested in meeting with recipients of your same organ type? Are you unable to make evening meetings yet would like to connect with TAO? Now you can! Several TAO members have been meeting on a regular basis to discuss their transplant issues based on the organ they received. Please contact the individual with the group you would like to meet with. The contact person will set up the time and place to meet and TAO will place this information in the Transplant Times and on the TAO web site. It may be for coffee, lunch or breakfast depending on the group's wishes. So feel free to contact the organizer and get out and swap info, meet new people and share transplant issues.

Heart:	Norm Breen	425-2156
Liver:	Bernice Eblovi	421-0531
Lung:	Joanne Schum	671-7635
Kidney:	Bonnie Haefner	391-3555

Lung Recipients and Candidates

MIKE'S NEW YORK DINER - 3423 Winton Place
(S. Winton Road and Brighton Henrietta Town Line Road Plaza)

1. Tuesday, January 11th - NOON
(The first meeting will be introductions, planning, ideas, and getting some topics to discuss.)
2. Monday, February 7th - NOON
3. Monday, March 14th - NOON

We will also discuss other possible locations, or day of the week for future gatherings. Mike's is centrally located and easy to get to from all directions.

Call or email Joanne if interested: 671-7635
twoluckylungs@juno.com

The Liver Bunch Lunch Group

Will be meeting on Tuesday, February 8 and Tuesday March 8 at the CRACKER BARREL RESTAURANT on Hylan Drive at 12:30 pm.

Liver recipients and candidates are welcomed.

Transplant Times

Submission Deadline

For April / May 2011 issue: Monday, March 7, 2011

Articles / ideas email to:
auggieday@aol.com or
kbliek333@gmail.com

or send by mail to:
TAO, PO Box 23552, Rochester,
NY 14692-3552



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TAO / Rochester Membership Application

No one is denied membership because of financial considerations

- DUES: \$20 Family \$100 Institution New Member Renewal Date unable to make dues payment at this time

Extra contributions to help our organization are always welcome, and are tax-deductible. Make checks payable to: TAO of Greater Rochester, PO Box 23552, Rochester, NY, 14692-3552.

Name (please print) Spouse/companion

Address City State Zip

Phone () E-mail

- Candidate/Recipient Family Member Donor Family Friend Professional

Candidate/Recipient information: # of Transplants Hospital

Date(s) Organ(s)/Tissue(s)